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**VOR Weekly E-Mail Update**

**July 18, 2008**

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**STATE NEWS**

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## **1. National: Deaths of developmentally disabled in home-care settings should get closer reviews: GAO**

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**July 09, 2008**

States should more thoroughly investigate deaths of people with developmental disabilities who were receiving home- and community-based services for care, according to a new government report. The Centers for Medicare & Medicaid Services should pressure states to review such deaths more closely, the Government Accountability Office says.

"Concerns about deaths resulting from poor quality of care and inadequate oversight of individuals with developmental disabilities receiving community-based care," compelled Sen. Charles Grassley (R-IA) to request the report (GAO-08-529).

The GAO interviewed officials in 14 states and found they varied widely in how they reviewed the deaths of individuals with developmental disabilities who received care under Medicaid waivers. Some reviewed only unexpected deaths, for example. Four of the states added extra steps to their reviews, which produced "greater accountability and transparency," GAO report authors wrote. They call for more in-depth reporting, which Health and Human Services officials countered would not be in line with other groups' reporting requirements.

The report can be found at [www.gao.gov/new.items/d08529.pdf](http://www.gao.gov/new.items/d08529.pdf).

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## **2. Maryland: Families Fight to Keep Rosewood Center Open**

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**By Christian Schaffer**

## **ABC News 2 - Baltimore**

**E.W. Scripps Co.**

**July 14, 2008**

Dozens of families say closing the Rosewood Center in Owings Mills puts their loved ones at risk. They want to keep Rosewood open -- and now they're getting some help.

There have been reports about trouble at Rosewood for years. State regulators have documented cases of poor treatment of residents, and crumbling facilities. Earlier this year Governor O'Malley announced that the state would close Rosewood.

But many families say Rosewood is the only home their loved ones have ever known. On Sunday, some of them came to Rosewood to protest the closure. 'The governor has made a bad decision; he thinks it's good but he's had bad advice,' said Harry Yost, whose son Larry is a Rosewood resident.

In January, Governor O'Malley announced that Rosewood would close within 16 months. All of its residents would be moved to group homes with treatment options specifically designed for them. At the time, he said, 'On balance I have to believe that living in community and the positives that flow from that far outweigh the disruption in the here and now.'

Harry Yost's son Larry is blind, deaf and can't speak -- because of a meningitis infection as an infant. He's lived at Rosewood for 45 years. In all that time, Harry Yost says he's seen no abusive treatment. He says community-based centers can't guarantee the same level of care his son has received. 'The advantage that we have here versus going out into a group home is that these people that are here, even the sub-contractor people, are trained,' he said.

Now, Yost and other Rosewood families are getting help from families with loved ones in the state's two other residential treatment centers -- Potomac Center in Hagerstown, and Holly Center in Salisbury. They have similar concerns about the level of care at group homes. 'They just have no business in a care situation that cannot be controlled nor is very consistent,' said Doug Wantling, whose sister lives at Potomac Center.

They worry if the state can close Rosewood, it can close their facilities too. 'We will fight. We are joining in this fight because we are all in this together all the families across the state,' said Marshall Rickert, whose brother lives at Holly Center.

Harry Yost says there are about 70 families at Rosewood who don't want the facility to close. Their plan is simple -- in order to move their loved one, the state needs a family member to sign a consent form. Yost and the others say they won't sign.

It's not clear yet how the state will handle the situation; a spokesman for Governor O'Malley did not return a phone call for comment Sunday

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### **3. California: Stalemate impacts homes for disabled**

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**By Sandy Kleffman**

**Contra Costa Times**

**07/11/2008**

Few people are following the state budget impasse in Sacramento with as much anxiety as Steve Zolno, co-owner of 11 homes for disabled children and adults in Contra Costa County.

Hundreds of such homes across the state will be among the earliest casualties of the budget stalemate. Their funding will evaporate within the next week or two as a state contingency fund runs out of money.

Zolno and his business partner, Lupe Henry, are worried how they will continue caring for their fragile clients.

"It's not like we can cut corners," Henry said. "I can't tell my staff to come back in two weeks or reduce the amount of food we buy.

"We shouldn't have to be in the middle of their haggling," she added. "It's distressing and I think it's just unfair."

No quick resolution is in sight for the budget showdown as lawmakers grapple with an estimated \$15.2 billion deficit. Democratic leaders favor tax increases to avoid hefty service cuts. Many Republicans oppose tax increases and favor more belt-tightening.

Budget delays have become an annual ritual in California. In the past 30 years, lawmakers have had a budget in place by the July 1 start of the fiscal year only a dozen times.

But this year is different, Zolno said.

In the past, he and Henry have been able to obtain loans to tide them over until the budget is approved. But the clampdown on credit prompted by the national mortgage crisis has made it virtually impossible this year, Zolno said.

He has been trying to obtain a loan for three months.

"Nobody has seen anything like this before," he said. "Nobody knows what we're going to do."

The intermediate care facilities that serve the disabled across the state are almost entirely funded through the Medi-Cal program. As a result, they will lose nearly all of their income when the state contingency fund runs out, said Gary Macomber, a Sacramento-based consultant who works with such facilities.

"Some of them can carry on for a week or two," he said. "Some will be in dire circumstances and not be able to make payroll."

Unlike nursing homes and hospitals, which also may have Medi-Cal funding delayed, homes for the disabled often are mom-and-pop-type operations that don't have large corporations to turn to for help or other funding sources such as Medicare.

"There is no ability to cost-shift or borrow money from another program," Macomber said. "So it's very problematic."

Zolno and Henry operate homes in Concord, Antioch, Pittsburg and Oakley. Each houses about six developmentally disabled children or adults in family-type settings. Many are quadriplegic and are fed through tubes in their stomachs. Some have cerebral palsy. Others have frequent seizures.

"They're beyond what their families can take care of," Zolno said.

When the funding stops, Zolno and Henry estimate they will lose about \$100,000 in income a week for their firm, New Way Services. They worry about keeping staff members to care for their clients if they are unable to pay them.

The state has a \$1 billion contingency fund, plus \$1 billion in federal funding, to pay institutional Medi-Cal providers during such budget stalemates. Last year, the fund lasted until July 24. This year, it will run out of money about the same time, predicted Toby Douglas, deputy director of health care programs for the state Department of Health Care Services.

Two Democratic Assembly members, Cathleen Galgiani and Mervyn Dymally, have introduced emergency legislation to add to the contingency fund to ensure that homes for the disabled, adult day health care centers and other organizations continue to receive funding.

But both bills are stalled. Zolno accuses Senate President Pro Tem Don Perata, D-Oakland, of holding up the measures to pressure Republicans to reach an agreement.

"In the meantime, we have very vulnerable people whose lives can be affected here," Zolno said.

A spokesman for Perata denied that the measures were being held up as a political tactic, and he said Perata's focus is on ending the impasse.

"It's just the plain fact that the state is nearly out of cash," said spokesman Andrew LaMar. "As a policy, we're not going to be approving massive appropriations for programs like this until the budget is solved."

While Zolno worries about the stalemate, others are already feeling the pinch from previously approved cuts.

Howard Strause, owner of Ridgecrest Pharmacy in Walnut Creek, is coping with a 10 percent reduction in Medi-Cal rates that went into effect July 1. He supplies medications to the people living in New Way Services homes.

"All of a sudden, I'm losing money on my prescriptions," said Strause, who operates one of the area's few remaining independently owned pharmacies.

A monthly supply of Seroquel, an anti-psychotic drug, costs him \$830, he said, but Medi-Cal pays him \$786.

He loses \$30 on a seizure control drug called Keppra that costs him \$554.

"Right now, I'm dipping into my savings but at some point I'll have to get a business loan," Strause said.

"I'm at a loss of what to do. My concern is the clients and their well-being. If I don't send a medication, these clients could end up in an emergency."

Last year, Gov. Arnold Schwarzenegger signed the state budget on Aug. 24, the third-longest budget standoff in 30 years. The delay put funding on hold for hundreds of Medi-Cal providers, nursing homes, adult day care centers, child care agencies and others across the state.

This year, Zolno and Henry are hoping for a quick resolution.

State lawmakers "have got us all in the middle of this," Henry said. "This year is far more difficult than it ever has been. We're at the end of our rope here."

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#### **4. Massachusetts: Making the wrong move**

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**Summary:** "The state says they're going to move my brother into a community setting," she said. "He's already in a community. They don't know or care about that community."

By Kevin Cullen

Globe Columnist

June 30, 2008

Their baby, their Debbie, turned 24 so Ed and Margaret Braga had a little party yesterday at their house in Arlington. It was hot and there are 25 steps up to the front door.

Debbie Braga's 31-year-old brother David couldn't make it. He has all sorts of health problems and rarely leaves Seven Hills Pediatric Center in Groton, where he has lived since he was 11 years old.

"We had him home for Father's Day, and it was a good day," Ed Braga said. He was sitting at the kitchen table and Margaret sat next to him and she nodded and agreed it was a good day.

They don't know how many more good days their David will have. They just found out the state wants to move David and 30 other people out of Seven Hills to a smaller facility.

This is the result of a lawsuit that has nothing to do with the Bragas and other families who know only that their children have survived and thrived at Seven Hills, long after some experts said their kids would die in childhood.

Nobody from the state, nobody with a medical degree, has bothered to sit down with the Bragas or any of the other families and ask them if they thought moving the people out of Seven Hills is a good idea.

Last week, at the annual Seven Hills family picnic, Ed Braga pulled aside some doctors from Children's Hospital, the hospital that got Seven Hills up and running in the first place, and asked them whether they thought it was a good idea.

"They think the same thing we think," Braga said. "They think this is a really bad idea. They think this will really threaten David's health and the health of the others."

Margaret Braga remembers bringing David home for the first time, seven months after he was born, thinking she could love her little boy back to health. But the oxygen didn't reach his brain soon enough, so he was mentally retarded. He had cystic fibrosis. He was a quadriplegic. His digestive system was a mess. His respiratory system was a mess.

Margaret would lie awake at night, listening to her son gasp for air, unable to sleep because she thought she had just heard David take his last breath. As David got older and heavier, they would struggle, carrying him up those steep front stairs.

"I was like every mother with a seriously disabled child," Margaret said. "I thought just my being a good mother would heal him, but it didn't."

Seven Hills saved more than David's life. It saved his parents and his five siblings, all of whom had been devoted to caring for him and keeping him in the family home.

And now, just like that, someone who has never met the Bragas, never spoken to them, never sat at the kitchen table, listening to the stories, the love, the pain of putting David there in the first place, the doubt, the reluctant realization that it was the right thing to do, has all the power. Somebody who knows none of this, who has never seen the photograph of David in a tuxedo at his sister's wedding six years ago that sits on the bureau just inside the front door, this somebody says they know what's best for David Braga.

"Don't we have the right to say no?" Margaret asked. "Don't we have the right to say, 'If you move David and these other people out of Seven Hills you're going to hurt them, maybe kill them?' "

Debbie Braga scoffed.

"The state says they're going to move my brother into a community setting," she said. "He's already in a community. They don't know or care about that community."

Ed Braga looked out the window. The guests would be arriving soon and he had to get the food out and had to be a good host even as he harbored a bad feeling.

"They're gonna kill him," Ed Braga said, standing up. "If they push him out, they're gonna kill my son."

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## **5. Washington, D.C.: Disabled Services Shrink In D.C.; 3 Residential Care Firms Quit, Citing Low Rates**

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By Daniel LeDuc

Washington Post

Sunday, June 29, 2008

Dozens of developmentally disabled persons in the District's care are being moved to new homes after three major care providers decided to stop residential services in the city because they said they were not being paid enough.

Almost 5 percent of the adults in the city's care -- 61 of 1,207 people -- have been moved or will be moved by mid-July.

The relocations have been disruptive for some of the residents, many of whom have behavioral issues and lack family members to watch out for them. Advocates say it has been extremely stressful for residents to have to suddenly adjust to new living environments, get new caregivers, change doctors and be sent to new treatment and social programs.

The moves began in January, when Philadelphia-based Resources for Human Development left. Chicago-based Human Resources Development Institute will leave the District on Monday. And PSI Family Services will dramatically cut back residential care by July 15, stopping residential care to all but a handful of clients.

It is the largest housing transfer of the developmentally disabled in the District in recent memory and comes as the city faces federal court hearings this year to determine how to improve its services.

"This is the first time we've had this many providers leave at once," said Sandy Bernstein, legal director of University Legal Services, which represents many developmentally disabled people in a long-running lawsuit against the District.

"When you move people, they have to get new doctors and have new staff working with them. It can be very traumatic."

Laura Nuss, the city's new head of services for the developmentally disabled, has been praised by care providers for her diligence in her new role. But she acknowledged that the moves had been a strain on many of the residents and her staff.

"You'd never choose this to happen, but the department has risen to the challenge," she said. "It has been a tremendous amount of change for our individuals and for us."

Nuss said that after the changes, more of the residents will be allowed to select programs and doctors, leading to improved care in the long run.

Tammy Barlow, a spokeswoman for Resources for Human Development, said its departure was prompted by low fees.

"The funds we received aren't adequate to run the programs needed in the D.C. area," Barlow said. "This is an issue that the District has to work out."

Representatives of the other departing companies did not return messages seeking comment.

The city kept rates the same for more than five years but last year provided a one-time jump of 19.2 percent. Nuss said future cost-of-living adjustments are accounted for in the rates.

The rates are set by the city's Medical Assistance Administration, which will soon be renamed the Department of Healthcare Finances. Under Mayor Adrian M. Fenty (D), Nuss, who runs the Developmental Disabilities Administration, has more say in setting future rates.

"We're not stopping at 19 percent," Nuss said. "We're actively going forward."

Care providers and advocates for the developmentally disabled say improved rates are essential to improving care because more money allows hiring of better staff and better training. Numerous providers contract with the city for residential services as well as medical and other types of care.

"The rates are simply too low," said Marsha Thompson, who formerly headed D.C.'s agency overseeing the developmentally disabled and now works for Careco, a healthcare provider. "You're not going to get the quality you need. If [a provider] can't make the dollars back that you invest, you can't stay in business."

The two providers leaving the District had been here two years, replacing another agency that had been criticized for poor care. Some providers say there could be more turnover unless rates increase.

Care of the developmentally disabled has been a long-running problem for the District, which was sued 30 years ago by advocates for residents in group homes.

In March 2007, U.S. District Judge Ellen S. Huvelle ruled that the city had failed those residents and called their care "inadequate."

In May, a federal court monitor reported that "serious deficits" remained in care for the developmentally disabled. Huvelle has ordered hearings in December to determine what must be done to improve care, possibly including a court takeover.

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***Tamie Hopp***

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